

DRAFT FOR CONSULTATION

1 [Information for the public]

2 **Healthcare services for head and neck** 3 **cancers**

4 **Understanding NICE guidance – information for the public**

5 **Introduction**

6 The National Institute for Clinical Excellence (known as NICE) has issued
7 guidance on the organisation of healthcare for adults with head and neck
8 cancers. The guidance recommends which healthcare professionals should
9 be involved in treatment and care, and the types of hospital or cancer centre
10 that are best suited to provide that healthcare – this type of guidance is called
11 'service guidance'.

12 It's important to remember that many service guidance recommendations
13 require large-scale changes in the way that a section of the NHS works.
14 Although such changes can't be made overnight, the NHS is working to put all
15 the guidance recommendations into practice.

16 **The key recommendations from the head and neck cancer service**
17 **guidance are summarised in the following sections.** More information on
18 these and the other recommendations is given in the full version of *Improving*
19 *Outcomes in Head and Neck Cancers*, which is available from the NICE
20 website (www.nice.org.uk). The full report also includes a summary of the
21 evidence that was considered when the recommendations were being
22 prepared.

23 Although service guidance does sometimes refer to appropriate forms of
24 investigation and treatment, it doesn't provide detailed information on these
25 areas. More detailed information on investigations and treatment for head and
26 neck cancers can be obtained elsewhere. (NHS Direct Online,
27 www.nhsdirect.nhs.uk, is a good starting point, with links to other sources of

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28 information on head and neck cancer.) People with concerns about their own
29 health should contact their GP or cancer team.

30 **Head and neck cancer**

31 Head and neck cancer is a general name for a group that includes many
32 different relatively uncommon forms of cancer. Most of these are cancers of
33 the mouth, lip, tongue (oral cancers) or the upper part of the throat (larynx and
34 pharynx). Head and neck cancers also include cancer of the salivary gland,
35 nose, sinuses and middle ear, which are relatively rare, and cancers of the
36 nerves and bone of the head and neck, which are even rarer.

37 The guidance also covers cancer of the thyroid, a gland in the neck that
38 produces hormones that regulate metabolism. Cancer of the thyroid is also
39 quite rare but, in other respects, is unlike the other cancers discussed, so it is
40 considered separately in some parts of this document.

41 Cancers of the skin or brain are not covered here. Lymphomas (cancers of the
42 lymph nodes), which often produce lumps in the neck, are discussed in a
43 separate guidance document, *Improving Outcomes in Haematological*
44 *Cancers*.¹

45 Head and neck cancers can often be treated successfully, particularly if the
46 cancer is diagnosed and treated early. Most head and neck cancers are
47 treated with surgery to remove the tumour, or with radiotherapy (treatment
48 using penetrating radiation), or with a combination of the two. Chemotherapy
49 (treatment with anti-cancer medicines) isn't usually used alone for these
50 cancers but may sometimes be used with radiotherapy (chemo-radiation).

51 Plastic or reconstructive surgery, to restore damaged areas, and specialised
52 dentistry may also be needed after the tumour has been removed. After
53 radiotherapy and/or surgery, people may have difficulty with eating, drinking
54 and talking, and may have to learn to live with facial disfigurement. People
55 who have their voice box (larynx) removed have to learn to cope with

¹ Available on the NICE website (www.nice.org.uk).

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56 breathing through an opening in the neck (stoma) and need to learn to talk in
57 a new way.

58 **Key recommendations**

59 ***Cancer Networks should decide which hospitals should*** 60 ***diagnose, treat and care for people***

61 National Health Service (NHS) cancer services are organised into networks
62 (Cancer Networks), which also include voluntary organisations and local
63 authorities. Most Cancer Networks serve between 1 and 2 million people. The
64 Cancer Networks should decide which hospitals in their area should diagnose,
65 treat and care for the different types of head and neck cancer patients. The
66 organisation of cancer services is being changed over the next few years. In a
67 few years' time, most head and neck cancer patients will be assessed and
68 treated in Cancer Centres that serve more than a million patients. This is to
69 allow Centre staff to treat enough people to keep their skills up to date and to
70 ensure that patients have access to all the specialist help they need.

71 ***Multidisciplinary teams should be responsible for every*** 72 ***patient***

73 A multidisciplinary team is one that brings together healthcare professionals
74 with all the relevant skills, knowledge and experience related to a particular
75 area of healthcare. A multidisciplinary team is needed because the diagnosis,
76 treatment and care of a person with head and neck cancer can be very
77 complex. People with head and neck cancers need a particularly wide variety
78 of professionals to care for them. When the professionals involved work
79 closely together, the patient is most likely to get the best care. NICE
80 recommends that everyone with head and neck cancer should be cared for by
81 an appropriate full multidisciplinary team.

82 NICE recommends that each multidisciplinary team (apart from thyroid cancer
83 teams) should care for at least 100 new patients each year. This is to allow

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84 team members to keep their skills up to date. The teams will be responsible
85 for assessing patients and planning their treatment and for patients' care.

86 **Special teams should care for people with thyroid cancer, and with some** 87 **rare or difficult tumours**

88 People with thyroid cancer should be cared for by thyroid cancer
89 multidisciplinary teams. These should be either

- 90 • head and neck cancer teams that are joined by experts in
91 endocrinology (the treatment of disorders of the hormones and the
92 glands that secrete them), **or**
- 93 • specialised endocrine cancer teams.

94 Because thyroid cancer is quite rare, these multidisciplinary teams will be
95 needed only in large hospitals that serve a population of more than 1 million
96 people.

97 There should be special multidisciplinary teams to provide treatment for
98 patients with cancer in rare sites and patients whose cancers present
99 particularly challenging problems (such as salivary gland tumours and those
100 that involve the base of the skull).

101 **Who should be in the teams**

102 The NICE guidance gives details of the types of doctors, nurses, other
103 specialists and support staff that all head and neck teams and all thyroid
104 cancer teams should normally include as a minimum.

105 People with head and neck cancer sometimes need additional care, so other
106 specialists should join the team when necessary. Teams that care for patients
107 with particular problems are likely to need more specialists at most meetings.

108 The involvement of psychiatric and psychological services is especially
109 important, because patients often have psychological problems, which may be
110 worsened by the effects of treatment.

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111 One or more members of each thyroid cancer team should be trained and
112 licensed to give treatment with 'radioiodine' (radioactive iodine). Radioactive
113 iodine treatment is often used to destroy any remaining cancer cells after the
114 thyroid gland is removed in an operation.

115 The teams should normally meet every week to discuss the treatment and
116 care of each patient for whom they are responsible.

117 **The roles of the teams**

118 The multidisciplinary teams are responsible for assessing patients' needs and
119 for planning their treatment and care. They also support and advise
120 professionals who provide care for patients outside the Cancer Centre.

121 Surgery should normally be done by surgeons on the team in a hospital with a
122 specialised head and neck ward where patients can be nursed. Patients with
123 small localised oral and throat tumours may be treated by surgeons in
124 peripheral hospitals who have appropriate skills and are members of the
125 team.

126 ***Arrangements for patients to see specialists should be clear***

127 When patients first see their doctors it is not obvious that they have cancer.
128 Most patients are first sent to a local hospital or clinic. If the doctor there finds
129 cancer (or strongly suspects cancer), patients are then sent to a major
130 specialist centre. Patients with cancer tend to do better if they are treated as
131 soon as possible. To make sure that this happens, there should be clear
132 systems and routes for patients to be seen quickly by specialists. These
133 arrangements should be agreed within each Cancer Network. Doctors,
134 dentists and other professionals who are likely to come across patients with
135 head and neck cancer should understand these arrangements.

136 NICE has recommended that patients with certain defined symptoms should
137 be seen urgently at a district hospital or neck lump clinic (see below). Patients
138 with certain defined signs or symptoms of thyroid cancer should be seen
139 urgently by specialists.

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140 **Patients with neck lumps should go straight to special lump clinics**

141 People who have lumps in their necks that are suspected to be cancer should
142 be seen rapidly at special lump clinics. If cancer is found, these patients
143 should be sent straight to the multidisciplinary team. Cancer Networks should
144 make sure lump clinics are available for rapid diagnosis.

145 ***Specialist services should be available to all patients who*** 146 ***need them***

147 Specialist services, such as specialist nurses, speech and language
148 therapists, dietitians and restorative dentists, have a crucial role in the care of
149 patients. Other specialist services, including psychological services, are also
150 needed by many patients. These specialists should be involved in the
151 assessment, support and rehabilitation of patients. NICE has recommended
152 that they should be available to all patients who need them.

153 **Clinical nurse specialist**

154 Clinical nurse specialists are nurses with experience and specialist training in
155 a particular area, who are skilled at helping patients.

156 The support of a clinical nurse specialist may help patients and carers to feel
157 less anxious, enhance their quality of life and help them to get problems dealt
158 with more effectively. Having a clinical nurse specialist who knows the patient
159 on the multidisciplinary team may make it more likely that the individual's
160 situation and concerns are fully considered in planning their care.

161 NICE recommends that patients should have access to a named clinical nurse
162 specialist throughout the course of their disease. Patients and their carers
163 should be given contact details for their clinical nurse specialist when they are
164 diagnosed. They should be able to contact their clinical nurse specialist if they
165 have questions about their disease or need help to cope with their disease or
166 its consequences. Patients and their families may continue to need help from
167 their clinical nurse specialist for some time after the patient leaves hospital.

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168 The clinical nurse specialist should be available to help and advise other
169 nurses, and other professionals, involved in the patient's care, to help them
170 deal with the particular needs of patients with head and neck cancer. Clinical
171 nurses specialists should also work closely with other team members and all
172 those involved in caring for the patient. They should be involved in
173 coordinating care for individual patients.

174 **Speech and language therapist**

175 Some people who have been treated for head and neck cancer may need
176 speech therapy for a year or more. The speech and language therapist should
177 discuss the planned treatment and rehabilitation with the patient before
178 treatment. The therapist should help the patient to deal with problems with
179 eating, drinking or communication.

180 **Dental services**

181 People with head and neck cancer often have complicated problems with their
182 teeth, faces and mouths. To deal with these problems, specialised dentistry
183 should be available for all patients who need it. A consultant with appropriate
184 experience should coordinate the dental care of patients after treatment.

185 **Nutritional services**

186 Both surgery and radiotherapy cause difficulties with speech and swallowing.
187 All patients who may need help and advice about their diet before, during and
188 after their treatment should have access to a dietitian. The dietitian can advise
189 the patient about tube feeding and about coping with the after-effects of
190 treatment.

191 ***Local Support Teams should provide long-term support in the*** 192 ***community***

193 Coordinated Local Support Teams should be set up to offer long-term support
194 and rehabilitation after treatment for head and neck cancers. These teams
195 should manage the aftercare and rehabilitation needs of patients, and arrange

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196 skilled care locally. A specific member of the team should coordinate the care
197 of each patient.

198 Patients and their carers should be taught about wound, mouth and tooth care
199 and how to deal with valves and stomas. They should be given contact
200 numbers for the members of the Local Support Team who can help them with
201 any problems.

202 ***More information should be collected***

203 To improve services, more information is needed about the effectiveness of
204 the treatment and care of patients with head and neck cancers.

205 Multidisciplinary teams should make sure that details of the treatment and
206 care of patients, and the course of their disease, are recorded and analysed.

207 ***More research should be done***

208 More research is urgently needed on the effectiveness of assessment,
209 treatment, aftercare services and rehabilitation. Because individual head and
210 neck cancers are relatively rare, both scientists and Cancer Centres need to
211 work together on research to improve treatment and care for patients.

212 Multidisciplinary teams should be involved in relevant studies.

213 **Further information**

214 It's important to remember that your local services may be a little different
215 from those described here – the NICE guidance sets out the way that the
216 head and neck cancer services should develop over the coming years.

217 If you have any questions about your health or the health of a member of your
218 family or a friend, speak to your GP. If you or a friend or relative has a head or
219 neck cancer and you have questions about the information here, or about
220 treatment and healthcare in general, talk to a member of the head and neck
221 cancer team. In addition, further information on head and neck cancer
222 (including the signs of symptoms of head and neck cancer) and support

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223 groups is available from NHS Direct (which you can access on the Internet at
224 www.nhsdirect.nhs.uk or by telephone on 0845 46 47).

225 NICE has issued guidance on supportive and palliative care services for
226 adults with cancer, which includes recommendations about issues such as
227 communication and the types of support services people should be offered.
228 Further information is available from the NICE website (www.nice.org.uk);
229 copies of the information for the public are available from the NHS Response
230 Line (telephone 0870 1555 455 and quote reference number N0XXX).

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236 Website: www.nice.org.uk

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238 Copies of this document are available from the NICE website or from the NHS
239 Response Line (telephone 0870 1555 455 and quote reference N0XXX). The
240 Guidance manual, *Guidance on Cancer Services – Improving Outcomes in*
241 *Head and Neck Cancer: Manual Update* (reference N0XXX) and a CD with all
242 documentation including the research evidence on which the guidance is
243 based (reference N0XXX) are also available.

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